

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 12, NO. 2/JUNE 1995



As Abilities Change

PAUL MARSHALL,
SHIRLEY McNAUGHTON &
PETER LINDSAY

This editorial has been written partly from Cape Town, South Africa, by Paul, and partly from Guelph and Toronto in Ontario by Shirley and Peter. We begin by announcing several changes for **Communicating Together**. For some time, we have felt that we would like to broaden the area of communication addressed by our magazine. In recent years, our focus has been upon the communication most of our editors knew best — that used by persons with cerebral palsy. Thanks to the initiative of two **Communicating Together** readers, now associate editors, we look forward to our new section — *Adapting*, relating to persons with an acquired speech disability. We welcome the authors of *Adapting*, Alda Steprans and Brian Pamplin. We welcome as well Suzanne Clancy and Tracy Shepherd, who have also joined our associate editor team. You can look forward to their articles in future issues.

Our broader interest area is reflected in a change to our masthead. When our associate editors met to plan the coming year, we decided to follow our magazine's name with "As Abilities Change". We hope those who use AAC as a result of reduced speech and physical capabilities, will find **Communicating Together** just as relevant as those who have lived with a speech and physical impairment all their lives. As Paul summarizes:

Communication is a life long process. From our first cry to the last breath that we take, we are constantly attempting to communicate with the world. As we learn

and grow, we develop language skills and more desires to interact with our own environments. It is a never ending process of living and learning. Language develops as we experience the ongoing events of our lives. How we think and react to these different circumstances in turn shapes the ongoing development of our communication. We have accidents that may cause our use of language to change. Sometimes at birth something happens, leaving an individual without speech. Strokes or serious illnesses can rob an adult of the speech they have always had. Even "normal" speaking people can have experiences that alter their ability to use speech for communication. The question is, how do we cope and how do we deal with life "as abilities change"?

Communication is a life-long process.

We hope **Communicating Together** will be able to offer articles of interest to a broader readership. As always we invite your suggestions. Having acknowledged the need to consider abilities changing in both directions, we return to the challenges facing all the AAC users that we know, resulting from changes in the world around them. Declining resources are having a strong impact upon inclusion, quality of care, technology transfer, advocacy and societal attitudes. As the effects of a changing society are felt, the personal challenge of each AAC user, attempting to realize his or her potential, is intensified!

We recognize that all the above topics intimately interact and impinge

on each other and have decided they can best be addressed together, rather than as separate themes. Thus, in this issue we look at several topics. Integration and segregation are featured in the articles by Nancy Gibbons and Annalu Waller and in Shirley's *Perspective*. Ways of coping are presented in Kari's Skallagrigg and our new *Adapting* section. *Consuming Technology* by Robert Haaf and *Contexts* by Geb Verburg address the impact of changing technology and of service provision models and call for a different direction for device development and a restructuring of the relationships between professionals and AAC users.

Our feature articles and the new *Adapting* section focus directly on the human considerations. They make us particularly aware of the stress on the entire family when one member has a severe communication and physical impairment, whether it be from birth or acquired as an adult. Opportunities to combat the loneliness often resulting from *integration* in the broader society, while being *separated* from others with similar challenges are presented in the *Readers Write* section and in a BlissNet announcement following this editorial.

We are delighted to welcome back an old friend to **Communicating Together** — Kari Harrington. Our long term readers will remember the many insightful articles Kari has written throughout the years. They also will have shared our concern when Kari resigned as an associate editor due to health problems. Recently, when we learned that Kari had written *Skallagrigg and Lillunau*, we saw it as a wonderful opportunity for Kari to share her thoughts again with **Communicating Together** readers. We have

serialized her story in four episodes, so you can look forward to a visit with Kari throughout this and the next three issues.

Paul returned from South Africa, dismayed by the attitudes toward persons with disability that he experienced while there. The lack of recognition of the potential of persons with speech impairments reminded him of his early childhood in Ontario. As we discussed some of the situations he witnessed, we realized how far countries which began their AAC work in the sixties and seventies have come. As we observe the life situations of the AAC users in these "advanced" countries, however, we know there is no room for complacency. They have many unmet needs in housing, education, work environments, recreation, and transportation, in addition to their communication needs. They and their families must not be abandoned as governments set agendas for debt reduction.

The more we learn about AAC, the more we become aware of what is possible for each individual who lacks functional speech, and the greater becomes the task of closing the gap between what is possible and what is a current reality for AAC users. Changing economic policies are intensifying this problem. Integration, with fewer supports to the teacher and increased class sizes, pressure for clinical prescriptions for equipment to be at the minimum level, advocacy and service groups being forced to reduce their supportive activities, attitudes hardening against those who cannot "make it on their own" — all combine to make life much harder for those with a disability.

Over the next year we'll continue to address the issues faced by AAC users in the mid-nineties, with special attention to their life situations during times of economic restraint and in a market-driven economy. We invite you to send us your ideas on any of the topics we have introduced in this issue.

§

BLISSNET Telecommunication for AAC Users

If you have a modem, and either an IBM computer with Windows 3.1 or a Macintosh with System 7, and you would like to communicate with those who use Blissymbols and/or print, contact:

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"Communication...Naturally!" That's the theme for the ISAAC 1996 Seventh Biennial Conference to take place August 7 - 10, 1996 in Vancouver, British Columbia, Canada. The Scientific Program and Exhibition offer a wide range of topics in the area of Augmentative and Alternative Communication. Both are open to researchers, practitioners, publishers, manufacturers, developers, and of course...AAC consumers!



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Reflections on the "S" Word

NANCY GIBBONS



Nancy Gibbons with her husband, Bob.

We are indeed fortunate to have two feature articles relating to segregation/inclusion as we re-visit the topic. The first is by Nancy Gibbons. Nancy is a wife-mom-singer-song-writer-volunteer and former teacher. She lives in Mississauga, Ontario with her husband, Bob, Elizabeth (18) and Matthew (22). Nancy helps us realize the contribution that can be made to a child's development from a well-planned segregated program.

Say the words "segregated program" in any gathering of disabled people and their advocates, and you are bound to wave a red flag for a significant portion of the crowd. Few among us are lukewarm on the issue. Sadly, our already small community seems to divide along philosophical lines over this hot topic.

We all want the same things — a happy, meaningful life with full access to all the activities and services our communities have to offer. We want independence, dignity and security. We want to be able to develop to our fullest potential and to be valued as contributing members of society. Where we

sometimes differ is in how to achieve these goals. Where we sometimes err is to assume that one approach fits all.

I am the mother of a nineteen-year-old daughter who is autistic and intellectually handicapped. Like all parents of children with special needs, my husband, Bob and I have had to make our share of tough choices for Elizabeth. Like many, we work towards the goal of integrating our daughter as fully as possible into the world. But while some students may enjoy the benefits of integration into regular classes, for Elizabeth, segregated academic and recreational programs have offered the best hope of reaching her potential and fitting into society.

When Elizabeth was a preschooler she was fully integrated into the neighbourhood play group that we mums put together. She played with the little girl next door. She went shopping, to social and recreational events, just like the other kids, even though her behaviour was frequently inappropriate. At that age the gap between her and her peers did not seem terribly large. Although the odd passer-by was overheard to whisper that what "that child" needed was a good "kick on the bottom", most people were generally willing to make allowances for her eccentric behaviours.

As the years went by, however, the differences between Elizabeth and her peers became more pronounced. By sixth grade, even the General Learning Disabilities stream was inappropriate for her. Self-directed and unable to attend in a larger group, she spent many days sitting at her desk in the corner playing with little things while the others worked. Her tantrums and constant need for one-to-one support

were disruptive. She was not being taught the life skills she needed and was not developing her abilities. She did not relate to her peers, did not participate in group activities and would wander off at class changes. She was a problem.

The following year, Elizabeth was placed in a class for the developmentally challenged within a regular middle school. There were six students, a teacher and a teacher's aide. What a difference! She was with teachers trained to work with students like Elizabeth. She was no longer the "problem" in the class, but one of a group with similar needs. The curriculum emphasizing life skills was more appropriate for Elizabeth's ultimate integration into society. For the first time she began to relate positively to her peers in an atmosphere of love and support — a true community. And at last, her talents rather than her deficits began to emerge.

As part of the language development curriculum, the class viewed the video of *The Wizard of Oz*. It soon became apparent that Elizabeth knew the whole film by memory, word for word. As the story unfolded, Elizabeth engaged her fellow students in miming the various parts, while she played Dorothy. With each subsequent viewing the students gained confidence in their new roles, and began to speak, sing, and act out the story. Soon the video gave way to an audio soundtrack recording, costumes were added, and excited peer tutors from other classes in the school volunteered to paint sets and props. Before long, a language class had evolved into a full-scale production and a date had been set to perform the work for the whole school. Word leaked out and other schools began calling, asking to see the performance.

On the day of the presentation of *Off to See the Wizard*, students were bused in from other schools. Two grade eight peer tutors introduced the play, telling the packed auditorium, "Seven E worked hard on this play and it's really great. They're our friends, and so you'd better pay attention to them". The curtain opened, and soon the audience was hushed as the story unfolded. The kids were amazing. They were proud and beautiful. They knew their parts, and acted as an ensemble. They were witty, and touching, and in complete control of the stage. When Dorothy had finally said, "Oh, Auntie Em, there's no place like home!", the whole audience leapt to its feet cheering. The cast bowed with pride and dignity. Their performance had received the ultimate tribute from the ultimate critics — their peers.

Performance at other schools followed. Elizabeth was honoured with the coveted Student of the Month Award, reserved for those who make a significant achievement or bring honour to the school. Far from being stigmatized or ghettoized by placement in a congregated class, these students were enabled to develop their talents and achieve acceptance and honour in the community. It is doubtful that the mainstream program and class size could have provided that opportunity to these particular students.

I venture to say that our experience of moving away from integrated activities towards more specialized programs is not all that unique. In my experience, the most ardent defenders of full integration at all costs tend to be the parents of young children just entering the school system, while the parents of adults with special needs often seem to seek out the support of the special programs. Perhaps this early optimism is good, and perhaps it is

connected with the denial phase of grief. Maybe a bit of both.

Without doubt, all disabled people have benefited from the work of integration advocates, as society has begun to become aware of issues of rights and access. However, to press for full integration and the elimination of special programs can create problems. We may lose the baby with the bath water.

As the philosophy of integration has gained popularity, we have seen more and more "special needs" recreational programs disappear. When we ask about this we have been told that those with special needs may join any program with volunteer support. However, the recreation department people are evasive about how many disabled people actually avail themselves of this opportunity.

How does it really work? On what basis do we integrate people? Do we integrate by ability, and put a nineteen-year-old developmentally challenged person into a learn-to-skate program for five-year-olds? Or, do we integrate by age and put her in a group of nineteen-year-olds who are practising for competition? How do we integrate someone in a wheelchair into a regular sport? Even when we find creative ways of approaching these questions, is the integration we achieve genuine or merely cosmetic?

As I see it, in a truly integrated situation, where all participants are treated equally, the level playing field is not level. Disability constantly demands a higher level of effort to achieve the same results. The disabled have to work harder and be "nicer" than others in order to fit in, and to elicit the extra co-operation of others that they need. At best, they may achieve academic success and acceptance in an "integrated" setting. At worst, they may be overwhelmed, patronized or just ignored.

In either case, the disabled participant will almost always be the odd one out, a statistical minority in most gatherings. Loneliness is inevitable. We human beings choose as friends those with similar interests, challenges and abilities, people with whom we can be ourselves and not work too hard. And so, after school hours, the classmates of the disabled will have each other and the disabled will, all too often, have no one but family. In this way, integration can turn out, ironically, to lead to isolation.

In a similar way, when our child is the only "different" one in a program, we parents may experience feelings of isolation from the other parents. That isolation may also bring with it actual rejection, as when a neighbour turned down the offer to share the driving of our daughters to Brownies.

Bob and I have really valued the segregated programs in which our daughter has participated as opportunities for networking. While our children participate in these activities, we parents talk. We share resources, ideas and common frustrations. We laugh together and support each other. These are times and places where we can experience community in a world where, all too often, our child is the different one. Ironically, these segregated programs offer us and our children a greater sense of self esteem and belonging than in a nominally integrated setting.

By all means, let us continue to press society for all that will enable us and our children to achieve dignity and independence, but let us not make the mistake of working against each other by assuming that our way is the only way. It is possible by different paths to reach the same destination. §

A PROPOSAL FOR INCLUSION

ANNALU WALLER
SHONA McDONALD

Our second feature article, by Annalu Waller and Shona McDonald, presents the case for integrating a South African child. Both feature articles share a common theme — the importance of choosing the route that will best meet the individual's current needs.

Background

Segregated education is not suitable for every child with special needs. Some children with severe disabilities require an able-bodied peer group to facilitate their interaction. The inclusion of children with disabilities into mainstream education can also benefit the able-bodied child. Including a child with special needs (SN) into a regular class is not straightforward, but with sufficient support and enthusiasm from the school, parents, and special education consultants, inclusion can be successful and productive. Including children with disabilities into the mainstream is relatively new in South Africa. The following proposal outlines a pilot study in which a specific child will attend a local primary school. It is hoped that by providing a rounded education for a specific child for whom able bodied peer group interaction is essential for her further development, this pilot study will identify ways in which mainstreaming can be implemented successfully elsewhere.

Why Inclusion?

South Africa has recently acknowledged that integrated schooling is of benefit to society as a whole. Barriers of fear and prejudice can only truly be broken down when people of different cultures are

encouraged to interact as children. The same reasoning underlies the attitudes of society towards people with disabilities. South Africa has applied a segregated policy to the education of children with SN for many years. Children are placed in special schools, training centres, or special care centres, depending on the medical diagnosis and “intellectual” ability of the child. Although this has been the trend in some other countries, educational authorities in Britain and North America no longer categorise children according to disability, but view children as individuals with individual needs. This approach espouses the idea that all children are individuals and should have access to education within situations appropriate to individual needs. Until recently the differentiation between Provincial and National Education has precluded any movement between different school settings. However the transfer of responsibility for the education of children with disabilities in South Africa from the Department of National Education to the provincial educational authorities will facilitate easier transfer between “special” and mainstream schools. The current financial climate precludes the establishment of any new special schools in South Africa. Mainstream schools will probably see an increase in pupils with special needs as the special schools will be stretched to serve those with more handicapping problems. As with racial integration, preparation and support is essential if the child with special needs is to benefit from a mainstream environment. Although the “academic” achievements of the SN child are often less apparent, the social advantages for both able-bodied and disabled children are extremely positive.

Models of Inclusion

Several models for including children with special needs into regular education are implemented elsewhere in the world.

1. *Unsupported inclusion* of an individual is only considered when the pupil is able to participate in the regular school environment without significant extra support. This model is usually appropriate for children with physical disabilities who are relatively independent once access to educational material and buildings have been ensured (e.g. use of portable typewriters, construction of wheelchair ramps). Many children with sufficient independence skills have attended township schools successfully in the past due to the absence of special schools in these areas.
2. *Supported inclusion* of an individual enables a child with significant disabilities to participate within a regular classroom environment. Successful implementation relies on a dedicated teacher aide who will support the child in the classroom. The roles of teacher and aide are well defined to ensure good interaction between the staff. The class teacher accepts the SN child as being part of the class. The aide is present to provide the teacher with support, e.g. adapting a worksheet to suit the child's physical ability; or facilitating the child's use of a communication board. The aide is not seen to be the

“exclusive” property of the SN child, but can be used to help other children as well. This model of inclusion has been successful with children who have significant physical and learning disabilities (i.e. mental retardation).

3. *Special units* are employed in schools where children need intensive one-to-one tuition. Children are included in the mainstream classes where possible and return to the unit when the child requires individual attention. The movement between mainstream and the unit depends on the individual child's needs and may vary daily. Classes such as “news telling” and “music” might be chosen as “inclusion” periods, whereas language lessons may require individual tuition. Units tend to suit individuals with language problems, behaviour difficulties and multiple disabilities.

4. *Special schools* are sometimes necessary for those children with severe physical and/or severe learning difficulties (mental retardation). These schools should be highly specialised and can provide a very useful resource for regular teachers who have SN children in their classroom.

Proposal for a pilot study

New concepts need to be implemented slowly in order to analyse their effect within specific situations. We are proposing to initiate a small project within Grove Primary School to accommodate an eleven year old girl with multiple disabilities.

Background

The motivation for this proposal has developed over a number of years. Michelle McDonald has been educated at home with a private teacher after having attended a mainstream preschool. Private tuition has provided Michelle with a good grounding in literacy and number work. During the past year her teacher has extended her subject base to include history, geography and science. Michelle has also been attending a private primary school twice a week for socialisation. Michelle has a full time aide who accompanies her to school and provides support during the school day. This arrangement has been successful, but it is now felt that Michelle needs a more structured week in which class discipline and staff support can be consistent. The present school is not the ideal situation for this to occur and it has therefore been suggested that we approach Grove Primary School with a view to admitting her as a pupil.

Michelle is well known to the Grove staff as both her sisters have attended Grove. Ursula Rontsche has indicated that she would be willing to have Michelle in her class. The aide will also be willing to work with other children in the class and Mrs. McDonald will provide support whenever necessary.

The Plan for Integration

Much thought has been put into an action plan for Michelle's inclusion into a mainstream classroom but the practical implementation will depend on observing her in the actual situation.

Michelle needs to be part of a peer group and as such needs to attend school on a regular basis. This might begin as “mornings only” arrangement, until Michelle's physical stamina has been determined.

This fits in well with the existing standard one class routine. The teaching methods used in Grove lend themselves to focusing on the individual child's abilities. Group and worksheet based methodologies and contract work suit Michelle. Group interaction, e.g. news telling at the beginning of the day, are also situations in which Michelle can be an active participant. The presence of the teacher aide will facilitate interactive communication within the group. In addition, the teacher aide will be able to assist the class teacher during group activities and when not needed by Michelle. Co-ordination between teacher and teacher aide will be facilitated by advance preparation and modification of worksheet materials so that Michelle can take part in class activities. Subjects such as second and third language work are currently unsuitable for Michelle and it is proposed that individual teaching should take place during these periods. Individual teaching will be the remit of the private tutor who will work in collaboration with the class teacher. Work covered in these sessions will consolidate classroom work. It will also provide an opportunity to reteach problem areas identified during class activities. Individual teaching will continue to take place at home for the time being. One of Michelle's greatest needs at the moment is that of self discipline. It is essential that the class teacher treat her as she would any other pupil. Wearing a school uniform will add to Michelle's sense of belonging to a peer group. It is hoped that this will encourage her to become more aware of her place in society. It may be decided that the class be prepared for Michelle's arrival. Although differences should not be over-emphasised, it is important that children

know that it is acceptable to ask questions about Michelle and her disabilities. The private teacher will need to see how the class teacher interacts with her pupils in order to prepare Michelle for a different methodology of learning. As far as we are aware this will be the first project of its kind in the Cape. Similar projects are being established in the Pretoria area and are proving successful because of the solid support base and enthusiastic involvement of the entire school staff. We hope this will help in the development of similar programmes within other schools in the Cape.

Advantages for Grove School

Being a laboratory school, Grove is seen to be a forerunner in new

developments within education. The inclusion of children with disabilities in mainstream education is the logical progression of integrating children of different cultures and it thus seems sensible to approach Grove with this proposal. Many of the problems associated with children who have English as a second language are also found with children who have multiple disabilities. The inability to communicate because of physical impairments has resulted in the development of several techniques which can be used to assist children with "traditional" language problems. We feel that the techniques used with Michelle will be of benefit to a range of other children at Grove. The advantages

for children in the mainstream to interact with their disabled peers are diverse but the social awareness that develops automatically is a vital part of any child's development. Michelle's parents and members of her support structure are in contact with local, national and international experts in the field of special education as a result of their work in "augmentative and alternative communication". Professional advice and other support thus exists to support this venture.

*The original proposal goes on to address financial considerations, future considerations and possible concerns. If you would be interested in obtaining the entire submission, contact **Communicating Together**. §*

ISAAC

ISAAC (International Society for Augmentative and Alternative Communication) is a transdisciplinary organization devoted to the field of Augmentative and Alternative Communication (AAC). ISAAC has 2,300 members in more than 47 countries, including 11 national/regional Chapters. Membership is international and is open to all persons who are interested in AAC.

The purpose of ISAAC is:

- * To advance the transdisciplinary field of AAC
- * To facilitate information exchange
- * To focus attention on work in the field

ISAAC MEMBERSHIP INFORMATION

An ISAAC **Chapter** is a national, regional or language group of members who address ISAAC's mission at the local level by acting as advocates for the development of AAC within their nation or region. Activities of the Chapters include local conferences, newsletters and other publications in the local language(s), and involvement in national policy-making issues. ISAAC strongly encourages and promotes membership in its Chapters. **Chapter membership includes membership in ISAAC.** If you live in a country or region *where there is an ISAAC Chapter*, please contact the ISAAC Secretariat to receive further Chapter membership information and current membership rates.

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Yucks and Wows!

NOLA MILLIN

*In this issue I am fortunate to have a number of **Yucks & Wows** to report. With the help of Tracy Shepherd, our new associate editor, I learned of a number of nonspeaking students who were willing to share what they felt were the major **Yucks and Wows** they experienced during their school years with regard to integration and inclusion. I am very pleased to have such diversity in age and experience, among the responses. Some of their experiences were very positive — clearly **Wows**. Other experiences they report are just as clearly **Yucks**! As we will be continuing the integration theme in our next issue, I invite you to contribute your **Yucks & Wows** related to your experiences in school.*

Do We Really All Look The Same?

When you see one person with a disability you haven't seen them all. Last fall, my friend John and I were taking a political science course at the University of Waterloo. I went to class every Monday and Wednesday. During class I would ask questions or answer them with the professor. I did well on my essays and midterm, having a cumulative 80% average. When I wrote my final exam, I had a pretty good feeling that I did well. Then the shock came. My transcript came over the Christmas holidays and it read: Political Science . . . F-. When I returned to school in January (thank God my parents didn't kill me) I called my professor and asked him how my mark was calculated. The professor said "If you had put the time and effort Dave put into the course, you would have passed".

I said, "This is Dave. Who do you think you were talking to?" The professor said "Oh #%&@!, I mixed you guys up".

Needless to say my mark was changed to an "A" and lucky for John, he received an "A" as well.

David Dame

Age 22

University Student

High School Experiences

My first yuck was math because I was never taught to do it right.

My second yuck was the doorways in the school hall, — so small that I kept banging into them with my wheelchair.

The thing that I hated most about high school was the uniform that made me look like the American flag: red, white, and blue.

In between classes in high school they would always play classical music and I didn't like classical music very much.

But mostly I liked high school.

I liked the fact that the school was big and it had an elevator.

I liked the opportunities that high school gave me. For example, I got to take a drama class and see what actors and actresses go through when they have to do a show every night.

I liked making friends. It seemed like I never had a problem in that area because people thought of me as outgoing. If someone were to ask me if I recommended high school for everyone, I think that I would say yes because everyone deserves to succeed or fail on their own.

Jamie Morand

Age 22

High School Graduate

My First Year at Century

My name is Sarah. I have a condition called cerebral palsy and am in a wheelchair. I would like to talk about how I felt before I came to Century Secondary School. I felt scared because I didn't know what to expect here. I thought, "Is it safe? Will I get lost? Would they touch my wheelchair?"

Now that I'm here, I realize what Century is all about. I realize that the students and staff are all nice now that I know them. I learned to speak appropriately and to keep my mind focused on classes. I learned how to respond if teachers asked me questions. I figured out how to get around all by myself, and how to get from one class to another.

The students were very shy when I first came. Now I think the students are starting to treat me as a classmate, and helping me in a way I never thought possible. The students are helping me by opening doors, and guiding me through the halls.

The teachers expect me to be responsible. Teachers treat me like other students and that makes me happy. I have to use some special equipment such as: a wet/dry board for drawing or writing words or numbers, a slant board for seeing things that are close up, large print, and a computer for typing. This computer talks and prints big letters so I can see it.

I have a special worker that comes around to all my classes with me, she is called a Teacher's Aide. My T. A. helps me learn in ways that I thought that I couldn't. She answers any questions that I possibly could have, and is very artistic in her drawings so I can understand the work. She writes for me because I can't use my hands very well. She also prepares my lunch so everything is in order.

I feel ecstatic about Century, and I think people will enjoy coming here. I've had great experiences here, and I expect a good future to come. I think people will learn a lot here.

Century has a husky as a mascot and this means bravery and strength to me. This is what the students can learn at Century, as well as being a family, helping each other, and being friends with others. I think that these qualities are important to learn.

*Sarah Ruttafi,
Age 16
Grade nine*

My Days At Dougall

A good experience is playing basketball at recess for the first time. I play basketball with Mrs. Evoy in the gym.

A silly experience at Dougall all started in science. When I found out that magnets aren't attracted to wands.

Let me tell you of a bad experience when I almost got frostbite outside. I was playing so hard that I didn't notice the wind coming toward me. It whammed me right in the ear and it hurt. So I went inside and told Mrs. Evoy. She didn't believe me at first and then the bell rang.

Another bad experience is when one of the kids hurt my feelings. It all started when I was waiting in line to get my teeth checked in the dental room. Then this kid came up to me and said I wasn't "normal". I cried! I went home and told my in-home worker when he got there. He told me, "You stand up to him and go and talk to the kid about what he did."

I think Dougall is a neat school.

*Mitchell Goulet
Age 8
Grade 3*

TEACHING AND LEARNING

Teachers' Viewpoints

COLLEEN MCGAFFEY

Special thanks to the following three teachers for sharing their teaching philosophies and their thoughts concerning integration.

While their classrooms may seem similar, the uniqueness of the students can be appreciated as each teacher describes her students in such caring terms. The philosophies discussed are not unique to these teachers or their students. They provide a foundation that anyone could grow on.

CANDACE GIBBONS, MSW

CHILDREN'S REHABILITATION
CENTRE, WINDSOR, ONTARIO

I am a primary special education teacher at the Children's Rehabilitation Centre of Essex County. I chose the area of special education and love the many challenges each new day brings. My teaching philosophies are derived from personal and professional principles developed in an earlier career in social work. Some of these teaching philosophies include: individualization, purposeful expression of feelings, acceptance, self-determination and the worth and dignity of every child.

My role is to facilitate the learning and development of each child to her/his maximum potential, both cognitively and emotionally. At our school this is a team effort combining the talents of students, families, therapists, aides, peer support, classroom assistant and teacher. The students in my class are six very unique little people with

individual levels of abilities. All of the children are wheelchair dependent with various levels of cognitive, visual and motor impairment. The ages range from five to eight years and each child's program stems from an Individual Education Plan developed by the team. My students are "non-verbal" but don't know it. Language is expressed daily in our classroom through eye gaze, switch and loop tape systems, voice output systems, vocalizations, hugs, giggles and sometimes tears! (theirs and mine)

The idea of integration conjures up a very satisfying image of all children happily sitting in a classroom together each accepting the other for the worthy individuals they are and each getting all of his or her own educational and social needs met. However, this dream has many social, economic and programming flaws. To truly express value on the worth and dignity of each child, we must remain focused on the individual needs of each child. Some children flourish in an integrated setting where all of the educational supports and curriculum modifications are made and others do not. Sometimes promises of support are made and not upheld for various reasons, often financial. My feelings and concerns are not centred around whether integration is good or a "just" thing, but rather around those who are at the heart of the issue - the children. If the school learning environment cannot meet the individual needs of each child what environment will? A continuum of services and placements that respond to individual needs must remain if we are to continue moving ahead in the field of special education.

In my classroom, the priorities are communication, socialization,

development of self-esteem and, in some cases, basic stimulation and maintenance of comfort needs. In general, the students need to develop a sense of their own abilities, to begin to view themselves as learners and to learn to communicate with their environment — face to face and/or in writing. All students need to develop listening and comprehension skills in order to enhance their ability to interact and get meaning from their environment. Last, but not least, the students need to develop skills in reading, writing and math, as individually appropriate. We must not lose sight of the basic goal when working on curriculum development for our students — that is facilitating the student to achieve her/his potential in communicating, functioning, and contributing to the world at large.

ANN SKELTON, TEACHER,

CHILDREN'S REHABILITATION
CENTRE, WINDSOR, ONTARIO

I have been teaching for 17 years — most of which have been spent in a segregated setting (a rehabilitation centre), with one brief sojourn into the regular system. Currently my class consists of eight children, ages five to eight, all with cerebral palsy, though their physical involvement and cognitive function vary significantly. About half of the children are non-verbal and several have visual limitations as well.

As a teacher with this group of children, I have come to view three basic principles as the core around which I must build each programme:

1. I am a developmentalist at heart, and believe strongly in the necessity of hierarchical

2. Due to the nature of my students' abilities, I believe in teaching within a functional context - with conceptual development actively linked to function within the everyday environment.

3. From years of working in conjunction with treatment teams, and availing myself of opportunities to take therapy courses, it has become evident that, in order for a programme to work, it must integrate all aspects of the student's development. To isolate cognitive instruction from physical, affective and functional skill development, is to teach in a vacuum, leading to frustration and misinterpretation on the part of the student and the teacher. Consequently, my perception of a teacher's role, is to organize the learning environment to include all aspects of development, and to facilitate the understanding of the inter-relationship and inter-dependence of seemingly disparate elements of life, therapy and learning.

This said, I can now discuss the ambivalence with which I approach integration. The first principle above should be compatible with any structured setting, and is not relevant to this discussion. The second and third principles are not so flexible. If a student is to be educated within a functional context, that necessitates placement within the regular system — for that is the “everyday environment” for children, and those are the pleasures and relationships, the challenges and expectations, that are childhood. To create an artificial environment in a sheltered setting is, at best, an approximation and at worst, a misrepresentation. The “functional context” is the real world!

However, in order to accomplish the integrated programming suggested in the third principle, a teacher must have the educational, and the experiential background to bring to the development, implementation and evaluation of the programme. A teacher would also need access to the necessary supportive and professional personnel. Unfortunately, due to financial constraints, integration appears to be an economic, not an educational policy, and funds for proper implementation are not likely to be available. Is it more appropriate for students to receive restricted programming in a suitable setting, or suitable programming in a restricted setting?

The goal of education should be to maximize the potential of each student; to equip each individual with the skills, knowledge and self-worth necessary for participation and acceptance in the world. Unfortunately, the structure necessary to achieve such goals appears to be a long way off!

M. DENISE EMERY, B.A. B.Ed.

KENT COUNTY BOARD OF
EDUCATION, CHATHAM,
ONTARIO

I currently teach a self-contained class of developmentally challenged, medically fragile students at South-western Regional Centre. Although this is my first year of teaching, I have worked within special education as an Educational Assistant for the past fourteen years. I truly enjoy the academic, physical and emotional challenges that each day brings and I try to meet these challenges with my students' needs in mind. I believe that it is my duty as their advocate to ensure that their individual needs are met on a daily basis.

Each of my students has an Individual Program Plan that helps to guide learning and maximize their potential. Most of my students are wheelchair dependent and have varying degrees of visual and motor impairments. They are also medically fragile and often suffer from upper respiratory infections. Although most are non-verbal, we (students and myself) tend to communicate with understanding through smiles, laughter and frowns. Sensory stimulation and socialization are a large part of our day as well as meeting personal needs for comfort and pleasure.

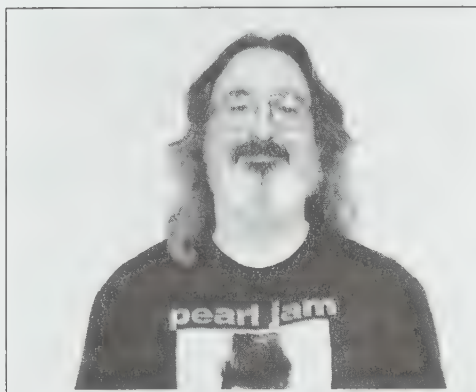
The goals/priorities within my classroom may and should differ from every other classroom, however, the process through which we achieve our goals should be the same - to teach with commitment and heart to the individual. Personal growth, a sense of self-worth, dignity and joy are qualities that I encourage and hopefully instill within my students as part of their learning experience.

Integration and mainstreaming have always been ideal concepts. For some students these concepts have become a reality to both their detriment and success. While some students thrive in these environments, others get lost in the shuffle. If our philosophy is to meet individual needs and to teach students to their potential, we cannot allow ourselves to risk either extreme - total integration/total segregation. Environment is an integral part of the process of learning. It should provide enriching experiences that assist the students in becoming contributing members of our society.

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Mainstream Computers versus Dedicated Aids Part One

ROBERT HAAF



As with (almost) every issue of **Communicating Together**, the plans for this column that are set down issue-by-issue are not exactly the articles that end up being written. I've found that this is more positive than negative, as several articles that had not been in the "original plan" have (to me) been the most satisfying to write. Well, it's happened again, but this time I think I can place the blame for it directly on one of the editor's shoulders! During our annual Editor's Meeting this past April, Shirley asked if I would consider discussing issues such as the amount of time it typically takes for state-of-the-art technology (virtual reality, for example) to move from being hyped in the popular media to actually being available to consumers in some usable form. Shirley's idea was to give readers a realistic perspective on how long such innovations can take to become products that anyone can use. Also during this meeting, the idea of technology obsolescence

was discussed, and how difficult it is for AAC users and funding sources to keep up with the almost overwhelming pace of technical development. I thought more about these ideas, and how they might fit into themes of integration and declining support to service delivery.

I began to realize that these issues help clarify many of the observations and frustrations I've recently been experiencing in efforts to provide communication technology to AAC users and their families. These ideas go well beyond some initial thoughts about new and obsolete technology, into issues that directly put AAC users at risk for ever being able to access technology that is truly functional.

Over the next two columns, I will present some of these issues and see if it will stimulate some thought and discussion about current problems with AAC technology, how it's provided, and the directions AAC technology development might take to overcome some very real barriers. As always, I appreciate your thoughts.

Recently I co-authored an article for a clinical journal in speech-language pathology, where we discussed the future of computer applications for clinicians in the field. Preparing for this article involved reading articles by Donald Norman and other authors who have given a great deal of thought to developments in computer technology and the impact they have on users. These writers helped to confirm some observations I've had about what is really happening with computer technology in recent years, and what it might mean to all of us as users of this technology.

A technical revolution

Over the past few years, we have been living through a technical revolution, one that has been relatively quiet but of massive proportions. While I am referring here to computer technology, I'm one writer who is not going to talk about the "information superhighway" (a term that I promise not to use again in this article!). The media hype aside, changes have been taking place in computers that have had profound effects on many aspects of our lives, and will continue to do so even if the computer in question isn't hooked up to a network. The personal computer is rapidly changing, from a tool used by those with training and education, to a tool that requires no training, one that anyone can access and make use of with less and less knowledge about the computer itself and how it works. Over the past few years, increases in computer speed, the development of optical storage devices (like CD-ROM) and an overall increase in the reliability and quality of hardware have allowed the development of software programs that bring audio, video, graphics, text, animation and other information together into one accessible package — one that can be used for education, entertainment, work and many areas only now being thought of.

Today's computer has changed so drastically that it isn't just an improved version of the computer we used a decade ago: the amount and extent of what it allows us to do has fundamentally changed. Most importantly, just about anyone can now use a computer. These increases in computer power, capacity and speed have allowed a parallel expansion in the control we have over

computer systems, and this is the core of the revolution I'm talking about. In fact, I would argue that this "control revolution" actually represents the most significant and exciting aspect of the changes taking place. No technology, no matter how powerful, is going to have an impact on our lives unless we feel comfortable with using it, and no amount of information is useful to us unless we can move through it and access what we want quickly and easily. A concrete example of this idea is in the similar 'evolution' that has occurred in audio technology, where CDs almost completely replaced vinyl records with unbelievable speed. Can it be argued that audio CDs provided much more music, or substantially better quality music? To some degree I suppose, but I think that the incredible speed with which this change took place had more to do with the control it provided. The ability to easily find, play and repeat specific songs, to program personal music sequences, and the fact that you can do all of this from your chair represented a fundamental change in the control technology, a change that almost everyone adopted as fast as they could pack up their turntables.

In much the same way, the more recent development of faster hardware and optical storage such as CD-ROMs have given software developers the opportunity not only to increase the amount of information available, but also to expand a user's ability to control the computer without having to spend significant amounts of time learning how to do so. Young children who haven't yet begun reading can now navigate their way through large information databases (such as the San Diego Zoo's "The Animals!") containing graphics, sounds and video on any number of topics and they can do so without any assistance from adults,

or without needing to know anything beyond basic pointing and clicking skills with a mouse. The sheer amount of information available means that a user can move through it in many different directions: A child using "The Animals!" can choose to listen to a series of narrated stories, or view colour photographs accompanied by primary-level text, or find more in-depth information about specific animals, all depending on their ability and interest levels. What's more, the 'path' that someone takes through such a program is no longer a simple straight line: every time you use the program you can explore different media and activities, get a new perspective on the information and better enhance and refine what you learn. In the same way, users can log onto a bulletin board service such as Apple's EWorld and be presented with a map resembling a small town, complete with a post office (for accessing electronic mail), shopping mall (for copying software) and other highly familiar buildings. The skills needed are some basic world knowledge and the ability to click a mouse. The days of learning a series of commands, typing them line-by-line on a keyboard, or spending hours trying to figure out even the simplest piece of software are rapidly becoming a memory.

Many people view the incredible pace of computer change with some degree of alarm. There is the sense that people who do not take computer courses, or who don't log onto the Internet daily, are being left behind. I firmly believe that this perception is by and large a false one. Computer technology is moving at blinding speeds, true, but it is moving towards the untrained user, not away. According to Norman and others, the "perfect" computer is one that will provide access to vast amounts of information, educational materials and entertain-

ment without requiring any new skills to operate. Users will be able to make their own way through the information using only existing skills: voice, pointing, touch, and their pre-existing knowledge about how the world works and is organized. Such computers will in effect be "invisible", so that users don't have to think about the machine or how to operate it. Instead they can focus on the information or activity itself. Norman's idea of the totally invisible computer isn't with us yet, but it is becoming a reality.

Accessing the new technology

It's always exciting to discuss new technologies and the potential that they offer. However, recently my thoughts have been turning more and more to how all of this applies to individuals with physical disabilities, and particularly those who use communication aids. Given that access (and therefore control) is often one of the largest hurdles to overcome with technology, you would think that the rapid changes occurring within the computer industry would translate into rapidly increasing ease of control for disabled users. You might also think that developers of AAC devices are together using the potential of new technology to develop more intuitive and flexible interfaces for disabled individuals. Keep in mind that all of the technology I've been discussing is not "cutting edge" or the "next big thing"; it's available right now to everyone, and at lower and lower costs.

If you assumed this was the case, you would for the most part be wrong. Currently, the majority of people who use some form of AAC for face-to-face communication are stuck in what amounts to a technological backwater, where specialized devices can provide only the smallest fraction of the computer's power. In the present situation, users of AAC

devices are a step removed from what the computer can provide, and the full potential of the multimedia computer has in turn not been creatively applied to the specific needs of those using AAC. It's not just that the communication technology currently available fails to facilitate access to all of the information, educational and vocational activities I've talked about. Rather current communication technology can act as a barrier to AAC users trying to fully access and use computers in the same ways as non-disabled individuals. In many cases, this is a barrier created by the devices themselves, one that is actually greater than any physical disability. I will begin with two specific influences on the provision of technology to the disabled that prevents them from having full access to current technology in their lives.

"Normal" technology transfer

Generally, the development of technology into usable forms requires some form of commercial incentive: what is sellable becomes available. This is why the "cutting edge" technology tends to first appear in entertainment and business applications, usually in that order. After it has been available to the non-disabled public for long enough, it becomes easier and cheaper to adapt the new technology to special needs. Of the three influences I will discuss, this is the one that is most influential, primarily because many people stand to make a great deal of money from it. Everyone in society is affected by this gap to some degree, and the degree depends to a large extent on how quickly the providers of a technology can profit from a particular group of users. Having said this, is anyone reading this surprised that "use of a product

by the disabled" is at the bottom of most developers' incentive lists (if it is even on the list at all?)

While some "specialty" software markets do exist, the most creative and useful products are clearly not designed and sold with the AAC user in mind. Probably by sheer chance as opposed to design, there have even been some instances where a product has actually met the needs of those with physical handicaps particularly well. Once it has been on the market for a short time, it has been updated and "improved" so that it better meets the needs of a business user and as a result is no longer as well suited for use by the disabled. (A specific example of this occurred with the Voice Navigator speech recognition system for Macintosh computers.)

So what can we do? Quite simply, I don't think we can reasonably expect that hardware and software developers will begin to work harder to meet the specific needs of the AAC user. Instead, we as AAC professionals need to become focused on ways to bring the AAC user to the computer, and thereby try to ensure that the wait AAC users experience with new technology is not much different than anyone else's. We need to consistently acknowledge that aside from needing communication devices, users of AAC need to access computers for all of the same educational, vocational and leisure purposes that we do. Why shouldn't the devices we provide offer all of this at once? As I will argue for the rest of this article, this can only be done by incorporating access technology and communication applications into existing computer platforms. This leads me to the second (and most important) barrier that AAC users currently face in taking full advantage of technology.

Continuing trend toward "dedicated" AAC devices

Recently, I attended a day-long conference where many of the major AAC device providers presented to a group (made up largely of clinicians) on the latest upgrades and revisions to their products. Many of the "advances" seemed to be taking AAC users in the opposite direction and isolating them from the computer. The manufacturers of dedicated AAC devices continue to work to provide features on their devices that are already readily available on computers, and not only do they usually end up reinventing a number of different wheels but they cannot do so with the same degree of speed, efficiency and success. All dedicated aids provide some way of storing messages and then retrieving them to be spoken. However, no dedicated aid that I can name is even a barely adequate word processor, nor can provide learning opportunities or help fill someone's leisure time.

Because dedicated aids cannot hope to match the computer's storage and processing power, they will not be able to offer the advantages discussed earlier at least for the foreseeable future. As noted above, the real innovations almost always appear first and most successfully on computer platforms. As manufacturers of communication aids continue to try and provide some semblance of the computer's ability in their devices, I think it's time that we once again consider whether this trend is really in the best interests of the clients we serve.

There's more to the story. I hope you'll join me for Part Two.

Reference

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KARI'S SKALLAGRIGG

KARI HARRINGTON

This is the first episode of Kari's most recent writing. We hope you will enjoy sharing her excitement as she discovers her own Skallagrigg.

Part One

The original *Skallagrigg* is a five-part story, seven hundred and twenty-eight pages long and all fiction. If I saw it in a book store, I would never even pick it up. Just looking at all of its pages and reading its title (that I couldn't really read) would put me right off. A good friend gave it to me for Christmas six years ago and I'm glad she did. *Skallagrigg* is about a girl named Esther who has cerebral palsy and goes on a search for Arthur and Skallagrigg. The book was slow reading at the beginning — actually it was boring — especially the part about the computer game. I thought the book would be all about this computer game and I was ready to stop reading it right there, but my friend had written a note inside the cover reassuring me that it would get better. So I kept on reading and it did get better!

What or Who is Skallagrigg?

When I read it the first time six years ago, I thought Skallagrigg was a special God for the disabled.

Six years later when another good friend told me that she was reading it, I thought to myself that I must read it again. I'm only in the second part and at chapter eighteen, but it's amazing when you put a book away for a few years. First of all, when I read *Skallagrigg* the first time I didn't realize Esther was

already dead and it was going back in time. I completely forgot or didn't realize I was reading some things that Esther had written on disks. So it's like a book that I have never read before.

About three people read it and all of us thought we should make it into a movie. It wouldn't be that hard to do and it would be a great movie!

Skallagrigg

This time around the book is more like a bible to me, especially with all the stories about Arthur and Skallagrigg. As I said before, I believed that Skallagrigg was a special God for the disabled. Now, even though I know who he really is, he is still that special God to me. It took a few very awful days when suddenly I felt I had to close my door, shed a couple of tears, and then pick up the book and read it. On three occasions, I looked out of a window to the sky and called Skallagrigg.

The first occasion I went out to see a play which I enjoyed very much, but whenever I stay up late especially in my wheelchair, I always reach my limit. I get uncomfortable. My lip will start trembling and I sometimes start seizing — the kind of seizures where I stare out into space. That night, I was in a lot of pain. I usually have a painkiller for my hip at bedtime, but I don't get it on these late nights. Somehow I believe Skallagrigg told me to hold on because the pain would go away when I got into bed and it did! He also helped me not to slip into seizures.

The next occasion was when my aide stood me at the bar expecting

me to stand up long enough to pull the commode chair away and bring my wheelchair up. My legs were caving in because my hips were swaying sideways. She told me to use all my strength and stand up straight. She said she wouldn't let me fall, but she wasn't going to pick me up either. I felt hurt as if all the strength I used wasn't enough for her. I have always found that holding onto a bar that is on an angle is difficult. I had a seizure while I was sitting on the toilet a while back before all this happened. I told my aide so she could report it. She said to me that having the seizure didn't have anything to do with standing at the bar. I felt more hurt because I couldn't just tell her I had a seizure. After my aide left, I turned to the window and sobbed. Then I heard my Skallagrigg talking to me. "It's okay Kari, I saw you using all your strength. I saw you. Don't cry." I felt better.

On the last occasion, I was in the pool. I was doing pretty well, moving my legs when they relaxed. I usually slip into seizures when I go into the pool. I figure that it has to do with the warm water which I really need or I won't move at all. If I shake too much my hip will tighten up making it hurt even more. Sometimes before I slip into a seizure, I feel alone as if there is no one around me and there is absolutely no sound even if there really is. This is the feeling I suddenly started to have — twice. But I felt an arm around me. It was my Skallagrigg stopping me from slipping all the way into the seizure.

To be continued next issue ...

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Some Thoughts on Integration

SHIRLEY MCNAUGHTON

*The following is an excerpt from a letter to a popular Canadian radio programme, Morningside. In the winter, a discussion of integration by three parents of children with disabilities was featured. The presentations were enthusiastically pro—total—integration. I want to share my reactions and comments, with our **Communicating Together** readers.*

I understand the hopes of parents who want their child to be accepted by their peers and their communities. As a primary education teacher who began in 1971 working with children with cerebral palsy who lacked functional speech, I have to express concern, however, when I hear a parent say that her son is in the regular classroom and his way of communicating is by indicating “yes” and “no”. One must ask, “What kind of socialization and inclusion can take place when the communicative capability of the conversation partners is so unbalanced?” If a “yes/no” response is all that the child is capable of, then I would question the appropriateness of the regular classroom program. If the child is capable of a more advanced communication system, then I would question how this can be achieved without the teacher receiving special training.

I have had the rare privilege during the seventies, along with other members of a rehabilitation team, of developing a communication system called Blissymbolics for children and adults with severe

speech and physical impairments. This system was originally created by Charles K. Bliss in the forties with the hope that it would become an international language. In applying this system to the communication of nonspeaking children, we have witnessed the impact of establishing a strong language base upon which literacy skills can be learned.

The children we worked with in the seventies were taught in segregated classrooms and their teachers received special training in the language of Blissymbolics. After two to three years, when we felt the child was ready (i.e. had the language base for the regular classroom), we approached the child’s school board. We demonstrated that the child with severe speech and physical impairments *could participate sufficiently* in the class program to be able to benefit from the academic activities of their peers. I have seen the results of such programs and realize the importance of teachers in the regular school program following through and supporting the specialized instruction with which the children began. Those who did, gave the children the support they needed. Those who did not, left the children to limited literacy achievement.

My concern, today, as I hear about the integrated placements of young children who have severe speech and physical impairments relates to the decisions often made, to provide the child with the communication system that best meets the *needs of the teacher* rather than that of the child. Pictures, which offer no language structure, are the communication method of choice *because they place the least demands upon the teacher*. Blissymbolics, as a

system which has a strong track record of providing the language scaffolding children need is rarely considered now in Ontario because the teacher needs training and must give time to the ongoing instruction of the child. The teacher is unable to take time away from the classroom to receive this training nor is there time available on an ongoing basis to support the child’s special communication and literacy needs. Clinicians, in anticipation of teachers not receiving the training, refrain from recommending Blissymbolics. If this were happening in the case of braille for blind children or American sign language for deaf children, we would be horrified. Because programs for children with severe speech and physical impairments have only been developed in the last twenty-five years, many of our school boards have not yet realized how important a child’s primary communication system can be. Fortunately this is not the case in many countries in Europe where Bliss is widely used with the young child and training is given to the teacher.

Integration, of course, is what we would all want for every child — but there is a need to think carefully and to be flexible as to its timing. Social integration should not have to be achieved at the expense of language, literacy and cognitive development and the establishment of a firm language base. Children with severe speech and physical impairments need longer for this to occur and need special help along the way.

We should remain open to these needs being met in a segregated class with a specially trained teacher.

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Introducing Ourselves

ALDA STEPRANS
BRIAN PAMPLIN



*As we initiate our broader outlook for **Communicating Together**, we are very pleased to welcome Alda Steprans and Brian Pamplin, who will be sharing their ideas in **Adapting**. Their focus will be upon what it means to adapt to an acquired disability.*

Meet Alda

Hello! My name is Alda. I am a nurse, who has the wonderful fortune of working in a chronic care hospital. Many people might wonder that I feel myself fortunate to be working in such surroundings, but indeed I do. Most people, even many other nurses and doctors think of chronic care hospitals as depressing. The one I work in, most definitely is not, although its residents are very severely disabled. What is it that makes working in such an environment, with such disabled people, so pleasant?

Two summers ago, I had the pleasure of meeting Brian Pamplin. Brian has an advanced stage of Multiple Sclerosis. He came to the

hospital for respite care, but decided to stay there to live. I was amazed at his decision, not only because Brian has a beautiful, caring wife and a loving ten year old son, but also because Brian had already made his home fully wheelchair accessible. What made him choose to stay in an institution?

Quality of life

Brian told me that he felt that his quality of life was better at the hospital than it had been at home. He liked the caregivers. He could get physiotherapy, occupational therapy and speech therapy almost every day and thus maintain his abilities. After talking to him, I became more and more obsessed with the concept of "quality of life". What is it that makes quality of life good for a severely disabled person — for that matter, for any person?

I was also very lucky that at this time, I had started my Master of Education degree at OISE, where I met both Peter Lindsay and Shirley McNaughton, the editors of this magazine. Quality of life was an issue that was seriously being examined, not only at OISE, but internationally. What a coincidence! It seemed only natural that my major research paper be on the topic of quality of life in this chronic care hospital.

To the surprise of many people, Brian was not the only resident who felt that his quality of life was good. My study involved only the few, highest functioning residents of the hospital I work in — those who can communicate about their lives. Some of the things they said, however, may also be important for those who cannot communicate. Many of the residents who participated in the study do have a great deal of diffi-

culty communicating.

All but one of the eight residents who participated felt that their quality of life was at least OK. Four felt it was Good. One evaluated it as Very Good, one as Very Poor. What elements are important to that quality of life? The residents identified competent physical nursing care, respect, daily activities, communication, technology and the environment as being vital. Questionnaires that were given to the residents revealed that different elements of quality of life were important to different individuals. What was most important to all of them, however, was *the ability to make choices*. The abilities to make choices, to have control, and to have competent nursing care, became the major themes for my paper. Many of the other elements the residents identified could be included in these topics.

For example, communication permits one to make choices and take control. What happens when one loses that ability to communicate by becoming unable to talk? How do we give our non-verbal residents choice and control? I do think that there are a variety of ways this can be done, but they all entail knowing the residents intimately. Nursing staff gain this knowledge through working closely with residents, and caring enough to discover and identify alternate communication modes, even body language and touch, for those who are most severely disabled.

Brian is a resident who often has difficulty communicating. On those days, at those times, he says that his life is harder. He goes to speech therapy frequently to help maintain his abilities, but when he is sick or tired, his voice becomes very soft. We have, with some difficulty,

finally discovered a way that Brian might be able to use to contribute his thoughts to this magazine. The Activities Department in the hospital has kindly made their computer accessible to Brian, whenever he wants to use it. This computer has a modified mouse and control panel, which Brian can use, despite his muscle weakness. The computer, unfortunately, cannot accompany him to his bedside, or communicate his needs when he is ill and too weak to talk. How can we help maintain his voice?

Meet Brian

It was a fairly easy transition from home to living in a chronic care hospital, because I was becoming a non-contributing family member at home. I found that in a day, I was just getting up, going through the motions of existing and waiting for my wife, Bernice, to come home from work. I felt as though I was doing nothing. My wife was doing a lot of the tasks that I used to do. She was becoming run down. We did get some help when I became more disabled. We used Meals-on-Wheels and I had a caregiver come to the house, but she was only there for two hours a day and she would not give me a shower. She mainly got me up. I had a fully accessible shower and washroom, but she did not want to lift me. I was going to get a lift through a hospital, but I went to a chronic care hospital for respite and decided to stay there.

The hardest part in coming to live at the hospital was leaving my home, but I liked the staff at the hospital. The care I was getting was like the care I would get from family. It was like they were looking after a brother. What I found hard was that I couldn't do simple tasks, like I used to. I physically couldn't do them. That doesn't bother me as much any more. What bothers me the most now is that my son, Gregory, does not listen to me. He

does things his own way. It hurts me when he doesn't take my advice. It could be just him growing up. He's almost ten. In the back of my mind I wonder if it's because I am disabled or in the hospital. I think he's had to grow up a lot in the past year. He's had to, because of changes at home and because of my absence. He's pretty level headed, but it's probably hard for him to deal with my being sick.

Another thing that made staying in the hospital easier, was that I had speech, physio and occupational therapy available to me almost every day. That helps me to maintain my abilities and skills and stay as independent as possible. It's a shame that because of fiscal restraint, these departments work only part-time.

One thing that cheeses me off are the nurses that come from the agency, because they don't know us. They're pretty good once they get to know the residents. It's very important to have people caring for you, who know you, who know how you like things done. With my having a speech problem, I find it difficult to communicate my wishes to new staff. Once that's done, it's fine. It takes a lot of energy to communicate, energy that I would rather use in other ways. The regular staff know how I like things done and they try to do them that way for me.

It's also very important to me that I can leave the hospital when I want to. I can travel around the neighbourhood in my electric wheelchair and with the help of wheeltrans I can go home, to a movie, or wherever I like.

After my hospitalization Gregory became depressed. None of us picked up on that depression. I feel that if I had been healthy that depression would not have occurred. I did not believe that I could help his depression. I thought that staying in

the hospital might help, because he would not have to see me being disabled on a daily basis. I know he thinks of me as a great dad, but he is not used to me being so disabled. I do feel that I am at a disadvantage compared to other dads. I can't pick up the football, like other dads do. My father did not play football with me and my brother and I felt it was an important thing that I had missed in growing up. I wanted to do that with my son. That's why I don't feel badly about my wife's new boyfriend. I feel that he gives my wife and son a lot of things I can't give them. I think that Gregory's depression was due to me coming into the hospital to live. It was the end of the line for Gregory's hopes. He had always hoped that I would get better. I think that Gregory is doing better now. When I recently went home for my birthday, he was very happy. He would not stop kissing me.

Although Bernice and I have not talked about it, I think that she felt robbed. If I had not gotten ill, we would still probably be together. I played hockey for six years after my diagnosis. I figured that as long as I was playing hockey, the disease would not get worse, but I was only in the early stages of MS. I've had MS for eighteen years. For the first six years I was fine, then I became progressively weaker. With each attack I became worse. My wife and I never spoke about this. I felt that she was coping with it as well as I was. I realized that she was not coping with it when she became more short-tempered with our son. Bernice is very independent and would not have felt she needed any help. Now looking back on it, she probably realizes she could have used some. My MS has had a big impact on all our lives.

§

PAUL'S PLACE

From Cape Town, South Africa — The Challenge

PAUL MARSHALL

As I sit here in Mike and Shona McDonald's office, talking about a squatter camp which we just saw on a daily drive, I think how blessed I am to live in Canada. Cape Town is a city of great beauty like the mountains and seas. It is a city where two different worlds meet and live together. But how, and why?

The two different worlds are the blacks and the whites, but common people live together nicely. If we go deeper than skin colour, the issues of life are the same. As human beings, we all want to have some type of quality of life.

When we talk about integration and inclusion, we must address two issues: how do we integrate or include people into the educational setting and how do we integrate people into the mainstream of society? These two questions are a major struggle for society. Each

human being, whether handicapped or not, should have the right to education and to take part fully in his or her own society. We all have the responsibility to provide this inclusion to each member of the human race.

As we go through life, we have many chances at things but sometimes we get an opportunity that is much larger than we are. This trip to Cape Town has been a real 'learning time' for me. I get the feeling that I am into something that is much bigger than what I can see. In South Africa, integration within education is an uphill battle. When a school assesses a child with a handicap and the test shows their I.Q. is very low, they are in danger of being labelled and stamped 'uneducable'. If the family cannot support their child, he or she will likely be placed in an institution where the state looks after them, and where all "quality" of life

is taken away and they spend their days in "human warehouses". For me, before the age of twelve, I couldn't read and many professionals thought I was slow. After I learned Bliss and started to read, people saw that I was intelligent and had something to offer to society, and they started to treat me differently.

South Africa has a great chance to start developing an "inclusion society". Inclusion is not based on values or standards. It is based on acceptance. I like this idea better. Like the western world, people must not be judged on the outer shell of colour or handicap, but rather on the soul of the individual. I hope we can realize that we are all responsible to our fellow-man to include each member into society.

South Africa, I wish you the best as you build a better future for the people who have disabilities. §

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Wouldn't it be nice if . . .

GEB VERBURG

This is another one of my stream of consciousness pieces. It has to do with my strong and prevailing belief that it is possible to structure rehabilitation and health care in general in a much saner and economy-encouraging way. I believe firmly that such restructuring must consist in large part of giving much more power to the customer (formerly "the patient") of the health care machine.

The second most important move is to remove disability from the field of health care altogether and into the jurisdiction of social justice. I believe that other parts of such restructuring would be the removal of rewards for conveyor belt medicine, ultra high tech testing, and the near gratuitous prescription of (expensive) drugs.

Power and the Helper's Dilemma

Client decision-making and client decision support structures must be maintained all through rehabilitation services as well as in medicine. This must include the right to get a second opinion (a third if necessary — beyond this there will be a charge). A system of services must include the professional or surgeon or physician being responsible for the accuracy and accessibility of the information provided, including information about prognosis, progress and treatment.

A very persistent imbalance in the fields of rehabilitation and medicine is the difference in power or perceived power of the *caregiver* and the *object* or *receiver of care*. The

attitude, of the doctor (alias god) vs patient (alias ignoramus, or the "pack-a-day-object", "the dysphasic" or "the [insert diagnosis or name of ailing or disabled body part here]") cannot continue. The same objectification happens at the professional level, where the helper stands apart from the helpee or client. I know that I am exaggerating and that what I am sketching here is really already beginning to change. But it is not changing fast enough and it is not changing far enough. Look closely at the completely counter-productive attitude exemplified in the doctor-patient or helper- helpee relationship. If we really want people to take responsibility for their own body, their own health, their own lifestyle then surely we must not treat them as if they are less competent, less responsible, ignorant, and unable to make decisions regarding their own life. How can we expect to treat people as invalids, as lesser beings, to ignore them or to barely listen to them when they are in our "care" and expect them to do the right things the minute they step out of our hospital (rehab centre, etc.)? How can we expect people to be strong and independent and able to make healthy life decisions when, while they reside in our institution, we do not really believe them or believe in their abilities?

Kindness and Hate

What is most damaging to the subjects of the services (sufferers of the attentions of the doctors, helpers, visitors, and friends) is the implication that ill people and disabled people are being done a favour. Even though I mention illness and disability in one breath

as it were, I do not equate the two. They do however engender this strange helper's syndrome.

Helping has the implication of charity, of kindness, of doing a favour, of "doing good". And while all that may be true, and some good may be done, the recipient of the good-doing is compelled to be grateful and is certainly expected not to hate the people that did the "good". And that is where I believe the root cause of the difficulty in the helper dilemma lies. For as Salaan Arrabey, a Somali poet, puts it in Margaret Lawrence's *Heart of a Stranger*:

*This is the way of life, this bitter way —
Kindness towards men begets their
secret hate.*

The irony of the helpers' kindness is that it has no base in fact. The helpers get more out of the deal, both financially and psychosocially, than the helpees. Surgeons easily make more than their patients (on average) and professionals make more than people with disabilities (again on average). Helpers also get more of a kick out of the socially rewarded act of helping than do the sufferers of the help. I may be a bit harsh. I do not mean to antagonize, I only want to point out differences in power, and the associated differences in roles and the potential for awkwardness that is inherent in such situations.

The solution to the helping dilemma is of course to do away with the helping, do away with the patient, and let health care and rehabilitation become a service provided to paying customers by professionals. The service could then be rated by consumer or other expert panels by criteria that are used to judge the provision of other services, e.g., effectiveness, satisfaction, cost.

I think it would help people with disability and their primary or community care givers (as well as everyone who comes to a hospital) if we restructure the "care" environment such that people are from the very beginning called upon to make, or at least be the principle decision-maker in their own health and lifestyle decisions and exercise these abilities in the relative "safety" or supportive environment of the rehab centre or hospital.

Professionalization of Consumer Input, Or Consumer Power Annexed

I was in Europe for rehabilitation conferences in 1993, in 1994, and again last May in 1995 and was thus able to witness the rise of the philosophy of consumer involvement in Europe (I should say some European countries) and its threatened annexation by professionals. Whereas in 1993, at the European Conference for Advanced Rehabilitation Technology (ECART) in Maastricht, very little was said about consumer input and the role of consumers in rehabilitation technology research and development (R & D), in 1994, at the ECART conference in Stockholm, there were a great many papers advocating the usefulness of consumer input. Still, however, there was no direct evidence that consumers were immediately involved in the process of evolving this participation in R & D. At the 1995 Technology Initiative for Disabled and Elderly People (TIDE) Second Congress in Paris, I was fortunate to be able to attend a session that presented both the best and the worst of European consumer involvement approaches that I have come across. The worst approach was luckily no more than an academic one but nevertheless a dangerous one because I am afraid that it might appeal to professionals. This approach advocated by a British organisation was one in which a multidisciplinary team of professionals (therapists, psychologists, ergotherapists, speech language pathologists, educational, nursing and engineering staff) would gather and/or analyse input from the client focus

groups. These multi-disciplinary teams would then decide what was required and what R & D should be pursued. In my opinion the creation of a small army of professionals between the consumers and the product developers would completely pervert the role and function of consumer input. By asserting that the process of extracting "valid data" from focus groups is a very complex process that must be carried out by professionals, this approach re-inserts the professionals back into a segment of the decision-making chain where the consumer ought to be directly in charge of the input and feedback. The process of development and more so the process of device prescription is already too professional-controlled, in my opinion.

In Ontario for example, a medical professional (physician) must write a prescription, a therapist or other professional must carry out an assessment in which the client also has a chance to make choices. In some instances there are other people — technicians, distributors and local professionals — involved in this prescription chain. My preference would be to keep this chain between user and device as short as possible, though it may have as many pendants (consultants) as necessary.

Study Circles

The best consumer involvement approach, presented at the TIDE second congress was initiated by the Handikap Institute of Stockholm and consisted of what is known in Sweden as the "Study Circle" approach. It is a tradition in Sweden for small groups of people to gather in their free

time to read a book and discuss/analyse it, or to study a new technology and learn about it, or to learn about other topics of interest to the members of such relatively ad hoc groups. These groups would meet from five to fifteen (+) times depending on the material to be covered and the way in which the group gels. What the Handikap Institute staff under Margitta Berglund has done has been to set up Study Circles on Rehabilitation Technology (RT). The nice thing is that the participants were people with disabilities who after having learned about RT went on to set up Study Circles in their own environment inviting other integrated audiences, who in their turn will go out and set up Circles and so on. This approach seems to be working out very well and it has the tremendous advantage that "consumers learn from and teach consumers". The RT related knowledge base of all potential users and of the people in their immediate environment increases as the Study Circles expand and will presumably start feeding back relevant critiques and suggestions for modifications to the developers and manufacturers. §

Have You Moved? We Have!

Please remember to let us know your new address. If possible, send an address label from a past issue.

Here is our new address:
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READERS WRITE

*We were very pleased to receive the following letter inviting **Communicating Together** readers who use AAC to join a pen pal club for those with a disability. In our last issue we printed a notice inviting AAC users to join a telecommunications project which would enable participants to communication using Blissymbols or print using their computer and modem. We have repeated a condensed version of that announcement on page 3 of this issue. Both these invitations emphasize the important message — Communicate Together, in whatever manner suits you best!*

To the Editor,

This letter is to inform you and your subscribers, that a new pen pal club for people with a disability has just started. The YACER CLUB is the Youth Advisory Committee's way of reaching those outside of our community. The Y.A.C. as we're known, is a group of young people aged fourteen to twenty-two who have a physical disability. We volunteer our time to represent the teen and young adult clients of Erinoak. Erinoak is a treatment centre for children up to the age of twenty-two who have a disability. The Y.A.C. is a working committee that includes sponsoring dances, BBQ's, bazaar booths, parent and staff information nights, public speaking, conference presentations, consulting other groups and educating the community, in the hope of mutual respect and understanding.

The most important thing for us is to provide the young people with opportunities for learning and practising life and socialization skills. Making friends and having relationships help foster self confidence, self respect and feeling good about one's self, no matter what the disability may be.

Two years ago we started a monthly Drop-in Club, where you can leave your disability at the door. Three bucks gives you three and a half hours to be with friends. During this time there are no parents, professionals or doctors, except staff leaders allowed. These hours are spent playing games, dancing, listening to music, pigging out, flirting, fighting, laughing and just being young. We realize that this is an opportunity those in small towns or rural areas would not necessarily have, so that brings us back to the YACER CLUB.

Our goal is to fight some of the loneliness that comes from isolation, by giving support and friendship through letters. In order for people aged seven and up across Canada to hear about this, we must ask for your help. Publishing our ad for your subscribers would be greatly appreciated.

Thank-you for any help you might be able to give.

Jennifer Thompson
YACER CLUB
Mississauga, Ontario, Canada

**If you like
to write letters,
get mail
or just make new friends,
then you may be perfect
for the
YACER CLUB.**

You must be over age seven and have a disability. We want to connect people over the country no matter where they might live, so everyone in small towns and big cities can have someone to talk to. Write, print or type and share ideas, helping hints, laughter and support.

Don't forget to tell us if you want to write to a girl or guy and be sure to tell us your age, name, address, postal code and send a self addressed envelope and adequate postage to:

YACERS CLUB
c/o Susan Canon
2277 South Millway
Mississauga, Ontario,
Canada
L5L 2M6.

We will send you all you'll need to send your first letter to your new Yacer friend.

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